

Abstract 360

TITLE: HIV Case Surveillance in Illinois Using a Provider Generated Patient Code Number:
One State's Experience in Policy Development and Implementation

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ISSUE: Recent therapeutic advances have resulted in a dramatic decline in AIDS incidence and mortality. As a result, AIDS case monitoring no longer provides a useful picture of the evolution of the epidemic. HIV case surveillance data are needed to provide reliable population-based data to guide public health programs. The CDC now recommends that all states conduct HIV case surveillance as an extension of their AIDS surveillance programs. Currently, 31 states require name-based reporting, a reporting method opposed by many advocacy groups under the supposition this policy causes at-risk people to avoid testing. Of the 12 states that use non-name-based reporting, only two (Texas and Maryland) have used a unique identifier system.

SETTING: In 1998, the Illinois Department of Public Health amended the AIDS Confidentiality and Testing Code and the Control of Sexually Transmitted Disease Code to require HIV cast reporting. At the request of some state legislators, the department convened a working group to discuss community concerns and possible alternatives that would achieve the goals of improved HIV cast surveillance and enhanced care provision to persons newly diagnosed with HIV.

PROJECT: Beginning July 1, 1999, as an alternative to name reporting, Illinois providers will be required to report cases of HIV infection using a provider-generated patient code number (PCN). To determine the effectiveness of the newly instituted surveillance system, the department will evaluate the completeness of cast reports, provision of risk information, reporting sources and the ability link the PCN to a patient. Should the proposed system fail to meet these criteria, reporting by name will become effective July 1, 2001.

RESULTS: This paper describes the process of implementing these rules, including consideration of deterrence issues, confidentiality concerns, logistics and community acceptance. The presentation also will report on progress toward surveillance system objectives, including: monitoring of HIV/AIDS prevalence and incidence; determining the individuals at greatest risk; planning and evaluating prevention interventions; facilitating care access; and projecting future epidemiologic trends.

LESSONS LEARNED: 1) The use of working groups involving community representatives is an effective way to develop alternative reporting approaches sensitive to the concerns of advocacy and community groups; and 2) a surveillance system using a provider-generated patient code number reporting system can be developed and evaluated.

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